

May 3, 2019

Renee Coleman-Mitchell, MPH Commissioner State of Connecticut Department of Public Health 410 Capitol Avenue, P.O. Box 340308 Hartford, CT 06134

Dear Commissioner Coleman-Mitchell:

I am writing in response to your letter of April 29, 2019, in which you state the Department's intention to release student immunization data by school. After much reflection and legal consultation, it is our belief that the release of such information is discriminatory and presents a potential HIPAA violation.

When this data is distributed regarding schools and daycares with small student populations, it may be relatively simply for parents and students to deduce which students are claiming a religious exemption, subjecting them to bullying and other forms of harassment. This is not mere conjecture; several real-life examples are readily available. Here is such an account from one of our members:

Years ago, we had one case of measles at one of the schools in our district. Moms were all panicking on the town Facebook pages, and I will never forget one mom saying, "it's a small town, we can figure out who it is!" There was no concern expressed for the health and well-being of the child. They had no idea if this child had been vaccinated or not. They had no idea if it was vaccine-strain measles (from MMR shedding) or wild-strain measles. They really did not know anything, except that one child in the district had measles - everything else was rampant speculation. Instant, vocal, self-righteous witch hunt. Bullying from people who claim to be against bullying. Is this really the kind of behavior you want to promote? There is

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no difference in the children with medical exemptions and religious exemptions the only difference is in other people's perception. Are you also going to release information on the number of kids with Hepatitis B? By the way, the child with measles fully recovered and nobody else caught it.

This story is illustrative of a larger problem: even if students or parents cannot determine for certain who is vaccinated and who is not, this data will lead to speculation, and undoubtedly lead to false accusations. That is, it is likely that people will presume that they have figured out who is claiming a religious exemption, even if they cannot prove it definitively. This is just human nature, reminiscent of the classic *Twilight Zone* episode, "The Monsters Are Due On Maple Street."

Curiously, you reference in your letter Regulations of Connecticut State Agencies § 10-204a-4, which mandates the collection of students' immunization data. What this regulation also states, however, is that "[a]ll immunization information collected by the department shall be confidential." The regulation does not say that only names shall be confidential, or that some immunization information shall be confidential; it clearly and unequivocally states that *all* immunization data shall be confidential. "Administrative rules and regulations are given the force and effect of law." *Hartford Electric Light Co. v. Sullivan*, 161 Conn. 145, 154, 285 A.2d 352 (1971). The disclosure of immunization information by school, then, is a violation of law.

Besides the fact that the release of this data is discriminatory in that it has a disproportionately adverse effect on those claiming an exemption from vaccination on the basis of their sincerely-held religious beliefs, this dissemination presents a potential HIPAA violation. As you are aware, HIPAA forbids not only the intentional disclosure of personally-identifiable information such as names and Social Security numbers, but also so-called "indirect identifiers" such as zip codes. Vaccination rates at specific schools within a zip code could reasonably be deemed indirect identifiers, especially in small student populations.

We therefore urge you to reconsider your decision to disclose this data. As you admit in your letter, Connecticut has had only three confirmed cases of the measles this year. This hardly constitutes an outbreak or any other public health threat, and thus does not justify this extreme action. Thank you for your considerate attention to this matter.

Sincerely,

LeeAnn Ducat Founder, Informed Choice CT